

Special Care Problems

Part 5: Bowel Incontinence

What To Do? A Guide for Families Caring for Persons with Dementia-Related Diseases

The principal author of this pamphlet is Deborah Monicken, MS, RN, Clinical Specialist-Rehabilitation, of the Department of Veterans Affairs Medical Center in Minneapolis, Minnesota. This pamphlet is part of a series on dementia-related diseases. This series was prepared by Kenneth Hepburn, Ph.D., Geriatric Research, Education and Clinical Center (GRECC) of the Department of Veterans Affairs Medical Center, Minneapolis, Minnesota.

Alzheimer's disease

People with Alzheimer's disease may become unable to control bowel movements. They may begin to soil their clothing or bedding. This problem, called "bowel (or fecal) incontinence," differs greatly from the loss of bladder control or "urinary incontinence." One problem can occur without the other. In either case, incontinence poses special care problems for you, the caregiver.

Urinary incontinence is fairly common among patients with Alzheimer's disease. Bowel incontinence occurs less often. In fact, many times bowel problems can be avoided altogether by starting the patient on good bowel habits long before any incontinence symptoms occur. Increasing the natural fiber and fluid in the person's diet, encouraging regular bowel habits, and keeping careful track of the person's bowel pattern will all help greatly.

If bowel incontinence does occur, it usually comes on later in the course of the illness. Whenever it occurs, the patient may not be aware of the problem at all or may be very upset by it.

Causes of bowel incontinence include medical conditions, side effects from drugs, and even severe psychological problems. Bowel incontinence may also be caused by the over-use of laxatives or enemas. In some cases, the patient may develop incontinence problems as a result of holding bowel movements for prolonged periods out of fear of pain due to constipation or hemorrhoids. Embarrassment over bowel accidents or anger or fear about being rushed or even forced through a bowel training routine may be part of the problem. Even changes in the person's diet, eating pattern or fluid intake can trigger bowel incontinence.

All cases of bowel incontinence should be checked promptly by a doctor. Many causes will respond to treatment, and the problem may be solved. Most patients can maintain bowel control if they are helped early enough. Even if the incontinence is caused simply by the progressing Alzheimer's disease itself, your health care team should have suggestions on how to cope with the problem.

As a caregiver, you will have to observe the impaired person carefully and report what you see to the health care team. You are also the one who will carry out any prescribed treatment or care plan. You will need to find ways to ensure the patient's comfort and cope with the extra work incontinence creates. You must also deal with any feelings and reactions of your own.

All these add up to a hard task, and you will surely need help. Don't be afraid to ask for it. Keep in mind that your health care team forms just one link in the care network that you must create to meet the needs of the impaired person and your own needs. The rest of this section offers suggestions for dealing with incontinence problems and finding any additional help you might need.

Observation and diagnosis

If a person suddenly develops bowel incontinence, the doctor will want to see him or her promptly. If you are the person's caregiver, you may be asked to observe the problem for a time. You may need to look out for signs of a pattern or signs of a worsening trend, for instance. You will also need to watch for signs of side effects from any prescribed drug. Then, using your reports, the doctor will be better able to make a final diagnosis and plan any treatment or care routine with you.

Reaching a clear diagnosis will be easier if you can answer certain questions for the doctor. As you care for the impaired person, try to observe the patient closely and record what you observe. (Use the space after each question to make notes.) Your doctor may have other questions or comment, too.

Questions:

Do bowel accidents occur just once in awhile, or is this a regular problem?

When do the accidents occur? After certain medicines are taken? After eating meals or after certain foods or drinks are consumed? After certain types of exercise?

Has the problem ever occurred before now?

When and how often does the impaired person have a bowel movement?

What was the person's bowel pattern before the incontinence began?

What is the consistence of the stool? (Hard, soft, or hard at first and then soft?)

Is the person having problems with diarrhea (loose, frequent stools?)

Do you notice anything unusual about the size, color or odor of the stool? (Is there blood or pus present?)

What kind of solid foods, including snacks, has the person been eating?

Have any changes been made recently in the types of foods eaten or in the amounts of foods eaten? In the types or amounts of fluids consumed?

Where do the bowel accidents occur? (In the bathroom? On the way there?)

Is the problem mainly that the person chooses odd places, like closets or the outdoors, for bowel movements?

Did you notice any changes in the person at the time the incontinence began? (Did the person seem more upset or confused than usual? Did the person's sleep patterns change?)

Were any changes made in the person's home or routine?

Is the person aware that a problem exists? If so, does the person seem upset about the problem or not?

Note: Be sure your doctor knows **all** the drugs being taken by the impaired person. This includes all over-the-counter drugs. If the person has been taking laxatives or stool softeners, discuss with the doctor whether to stop or cut down on these.

Treatment and management

Once your doctor has diagnosed the problem, treatment may be started for those symptoms that can be helped. You may be asked to carry out the prescribed treatment at home. This may be as simple as changing or stopping the use of any laxatives. If the doctor prescribes a certain drug or diet change, you will be asked to observe the impaired person closely for results and for any new changes.

The prescribed treatment may not work, or may only work in part. There may not even be any treatment for some cases. Even so, you and your health care team should still work together to manage the care problems that remain.

Your care goal in each case remains the same. You want to manage the impaired person's toileting in a way that preserves his or her comfort and self-esteem without making needless work for you. To do this you will need to keep careful track of the person's normal routines (diet, sleep and toileting, for instance) so you will know when a change occurs. You will also need to set up a regular toileting routine **as early as possible**. An established bowel routine will benefit the patient and caregiver, as the patient's abilities decline later in the illness. You must also help the patient avoid painful experiences (such as constipation or hemorrhoids). These can turn occasional incontinence into a regular pattern or lead a patient to resist needed bowel care.

Coping techniques

The following suggestions may be helpful to you. Discuss these with your doctor or nurse and make a plan. Then see what works best if a plan doesn't seem to be working, call the doctor or nurse back to discuss the problems you are having. Ask about any ideas you may want to try. Support groups offer you a good source of ideas. Other members may well have good tips for managing the very problems you are facing.

Review daily habits

Review the impaired person's daily habits for any patterns or cues that will help you. For instance, does the person usually have a bowel movement around the same time every day? Or is the person having a bowel movement after meals? If you observe the impaired person closely, you may also learn that certain behaviors seem to occur just before the accidents. In all of these cases, being aware of the pattern will help you take the person to the toilet before an accident can occur.

Make changes in the daily routine

Make some changes in the daily routine, if need be. Is the impaired person receiving regular exercise and a well-balanced diet? A diet including plenty of fluids and foods high in natural fiber will encourage regular bowel movements and help avoid constipation. A good diet would include fiber in the form of fruits, vegetables and grains and would reduce the amount of fatty foods. (Fatty foods include red meats, bacon, sausage and high-fat dairy products like ice cream and butter, for instance).

Establish a pattern

of taking the impaired person to the bathroom on a regular schedule. Aim for a pattern of taking the person to the toilet at least two or three times a day. Always use the same type of facility (either a commode or a toilet, not both). This will tend to make a stronger association in the patient's mind between whichever item is used and the need for a bowel movement. Be careful to include toilet visits right after meals. A reflex reaction called the "gastrocolic reflex" often gives people a strong urge for a bowel movement just after a meal.

Make sure the bathroom feels safe

and comfortable to the impaired person. Check the heating and lighting. Support bars or handrails make for easy movement to and from a sitting position. Be sure, too, that the toilet seat is stable and at a good height for the person. Devices are available that can change the height of the seat, if need be. A few magazines and/or a battery-operated radio in the bathroom may help make the person more comfortable, too.

Bowel training program

Consider trying a bowel training program. You may be able to work with your doctor or nurse to put the impaired person on a training program that will help prevent bowel accidents. To do this, you must control the person's meal schedule, what the person eats and drinks, and when the person goes to the toilet. You will also need to keep track of the amounts and kinds of solid and liquid foods given to the patient. Meals and drinks should

be given at the same time each day. The diet should include an increase in fluids and high fiber foods and should avoid problem foods or drinks. You will need to be sure that the person goes to the toilet at the same time of day each time, without rushing, approximately 30 minutes after a meal. The exact diet and schedule have to be adjusted for each person, and the whole procedure involves some trial and error, but most patients can be maintained continent in this way.

Note: Consult the doctor before using any over-the-counter laxative or stool softener. These may make an incontinence problem worse.

Supplies that can help you cope

If your efforts at management by these techniques have not worked (or have not worked as well as you might have wished), you might consider special clothes, supplies and equipment designed for persons with problems of incontinence. These products may be costly. You will need to weigh what you can afford to buy against the amount of help these products offer you as a caregiver.

Besides portable commodes, grab bars, handrails and adjustable toilet seats, a number of other products can help an incontinent person. These include adult briefs (diapers), pads, liners, slipcovers and sheets. Some may be washed and reused; others can be thrown away after one use. Some products absorb more than others because they contain a gelling material. These products also cost more.

Your doctor, nurse or pharmacist can describe these products and help you decide what would work best in your case. They should also be able to tell you where you can find these items.

Be sure to include the cost of all such materials in your planning. Shopping for the best buys will help you control costs. If you decide you want to try a piece of equipment, consider renting it for a trial period rather than buying it outright. For major items, you may even find that renting the piece over a longer period is still cheaper than buying it.

Living with the problem

If the person in your care has become incontinent, your caregiving role has been enlarged. You will need to observe the patterns of the problem and work with your doctor or nurse to plan techniques for coping. You need to figure out ways to plan ahead and prevent the problem, if you can, and to comfort the patient and clean up if the plan does not work.

As with other parts of your caregiving task, seek help with incontinence problems. Besides working with your health care team, don't be afraid to ask your family and friends for help. They can fill in for you at times. They can search out where to buy incontinence supplies and hunt for the best bargains for you. You may also want to hire help, either in your home or in a respite care facility.

As in all aspects of your caregiving, don't ignore your own needs and feelings. Even if you know that the impaired person is not causing problems on purpose, dealing with incontinence may make you feel any number of emotions. You may feel shock, anger, disgust, shame, grief, or a sense of being overwhelmed. You might even feel guilty for feeling this way. Try to keep in mind that the trouble is not the result of your being a poor caregiver. The problems are part of the disease itself and the caregiving role. Other people have been through troubles very like your own, so do not feel you must keep your problems to yourself. Speak to a friend or family member, a counselor or member of the clergy, or join a support group. (The Alzheimer's Disease and Related Disorders Association may be able to help you find a support group near you. Ask your health care team or a local hospital for a referral.) At times like this, sharing what you feel can be very helpful.